

The Hep-CORE Study:

*Monitoring European policy responses to viral hepatitis – the
central role of patients*

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Civil Society Forum, Luxembourg

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Why “Hep-CORE”?

Hep-CORE was created in the midst of important global policy developments on viral hepatitis

The name serves as an abbreviation for:

- Community,
- Opinion,
- Recommendations,
- Experts

Promotes recognition of hepatitis as a “core” challenge to be tackled – hepatitis is even a part of the Sustainable Development Goals



<http://www.who.int/hiv/events/first-hepatitis-summit-2015/en/>
(Accessed August 2016)



<http://www.hcvbrusselssummit.eu/elimination-manifesto>
(Accessed August 2016)/



Source: WHO Global Health Sector Strategy on viral hepatitis. Available at: http://apps.who.int/gb/ebwha/pdf_files/WHA69/A69_32-en.pdf?ua=1 (Accessed August 2016)

Hepatitis B and C

An action plan for saving lives in Europe

The experts' recommendation summary

Hep-CORE

Purpose of Hep-CORE:

“To evaluate the extent to which ELPA member countries in Europe and the Mediterranean Basin follow key international recommendations for good practices in addressing viral hepatitis.”

The investigative framework for Hep-CORE was drawn from *Hepatitis B and C: an action plan for saving lives in Europe* (recommendations in key action areas published by WHO, WHA, VHPB, EASL, Correlation Network, HBCPPA, ELPA, ECDC and US CDC between 2011-2014).

<https://www.britishlivertrust.org.uk/wp-content/uploads/Hepatitis-B-and-C-An-Action-Plan-for-Saving-Lives-in-Europe.pdf>



The Hep-CORE study is key

- Hep-CORE provides the only European viral hepatitis policy monitoring tool
- Uniquely, it is patient-led
- Provides a benchmark over time to measure policy gaps and improvements
- Casts a wide net in order to gather a comprehensive picture of each country's situation and the 25 European (and 2 additional Mediterranean Basin) countries as a whole



Hep-CORE

The 2016 Hep-CORE Report

Monitoring the implementation of hepatitis B and C
policy recommendations in Europe

European Liver Patients Association

Hep-CORE 2016

But where does this lead?

- Involvement of 27 patient groups led to over 15 presentations at national meetings, conferences, and summits and press coverage across Europe
- Brought patient groups to the forefront of the policy conversation and fostered key stakeholder collaboration



Hep-CORE presentation, Community Summit, ILC2017, Amsterdam

Publications and conference abstracts

HepHIV2017 – January '17

Poster No. P0201 HepHIV 2017 Conference

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Missed Opportunities for Viral Hepatitis Testing in Europe: a 25-Country Analysis

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INTRODUCTION AND OBJECTIVES

The 2016 approval of the WHO Global Health Sector Strategy on Hepatitis, coupled with the advent of better antiviral medications, has underscored the importance of hepatitis B virus (HBV) and hepatitis C virus (HCV) testing. The European Liver Patients Association (ELPA) carried out the Hep-CORE study to collect information regarding numerous aspects of national HBV and HCV policies, including testing-related policies.

RESULTS

Patient groups in many study countries reported an absence of HBV/HCV testing sites outside of hospitals for people who inject drugs and other high-risk populations (Figure 1). There was reported to be routine HBV/HCV screening for pregnant women in 88% and 44% of countries, respectively. In 23 countries (92%), blood donors were said to be notified if screening indicated infection with HBV/HCV; and of these 23 patient groups, 19 (83%) reported that blood donors in their country who are screened and found to be positive for HBV/HCV are referred to medical care. According to survey respondents, 17 countries (68%) include liver enzyme tests in routine medical check-ups, whereas only five (20%) include HBV/HCV risk assessment (data not shown in tables). Less than half of countries were reported to have widespread free and anonymous HBV/HCV testing services targeting high-risk populations (Table 1).

CONCLUSIONS

European countries must act to reduce missed opportunities to diagnose HBV and HCV, giving particular attention to testing accessibility for high-risk populations and to risk assessment during routine medical check-ups.

Hep-CORE

METHODS

In 2016, we asked patient groups in 27 countries to participate in a cross-sectional survey that asked about their countries' policy responses to HBV and HCV. The 39-item English-language survey, administered online to one patient group or coalition of patient groups per country, included questions about testing/screening sites outside of hospitals, screening of pregnant women, notification of blood donors, risk assessment during routine medical check-ups, and the existence of free and/or anonymous testing services. We present a descriptive analysis of findings from the 25 European countries represented in the study.

Figure 1: Number of countries reported to have HBV and HCV testing /screening sites outside of hospitals for high-risk populations (N=25)

Population	HBV	HCV
PWID	15	16
Prison	14	18
MSM	14	18
Sex workers	14	18
Pregnant	14	18
Healthcare workers	14	18
Migrants	14	18
Transgender	14	18
General	14	18
Other	14	18

Table 1: Proportions of participating countries where respondents reported the existence of free/anonymous HBV and HCV testing services targeting high-risk populations (N=25)

	n (%)	Free HBV testing	Anonymous HBV testing	Free HCV testing	Anonymous HCV testing
General population	9 (36%)	6 (24%)	9 (36%)	6 (24%)	6 (24%)
PWID	14 (56%)	10 (40%)	13 (52%)	9 (36%)	9 (36%)
MSM	12 (48%)	9 (36%)	11 (44%)	7 (28%)	7 (28%)
Transgender	11 (44%)	7 (28%)	10 (40%)	6 (24%)	6 (24%)
Sex workers	10 (40%)	7 (28%)	9 (36%)	5 (20%)	5 (20%)
Prisoners	14 (56%)	7 (28%)	13 (52%)	7 (28%)	7 (28%)
Migrants	6 (24%)	6 (24%)	6 (24%)	6 (24%)	6 (24%)
PLHIV	13 (52%)	10 (40%)	12 (48%)	9 (36%)	9 (36%)
Other	1 (4%)	0 (0%)	1 (4%)	0 (0%)	0 (0%)

Abbreviations: HBV = hepatitis B virus; HCV = hepatitis C virus; PWID = people who inject drugs; MSM = men who have sex with men; PLHIV = people living with HIV

HEP-CORE EUROPEAN STUDY COUNTRIES:

Austria	Denmark	Italy	Serbia	Ukraine
Belgium	Finland	Macedonia	Slovakia	United Kingdom
Bosnia & Herzegovina	France	Netherlands	Slovenia	
Bulgaria	Germany	Poland	Spain	
Croatia	Greece	Portugal	Sweden	
	Hungary	Romania	Turkey	



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Viewpoint

Restrictions on access to direct-acting antivirals for people who inject drugs: The European Hep-CORE study and the role of patient groups in monitoring national HCV responses

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ILC2017 – April '17

Access to hepatitis C treatment in Europe: findings from the 2016 Hep-CORE study

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BACKGROUND

While new direct-acting antivirals are now effective enough to cure more than 90% of hepatitis C cases, it is not known whether there are suitable policies to promote access to treatment in European countries. The Hep-CORE study collected information on viral hepatitis policy issues from patient groups belonging to the European Liver Patients Association (ELPA) and offers insight into this situation.

RESULTS

According to patient groups, 24 of the 25 study countries (96%) have national clinical guidelines for the diagnosis and treatment of hepatitis C (Figure 1). All types of direct-acting antivirals were reported to be available to all HCV-diagnosed patients in 16 countries (64%), while in four countries (16%), none were reported to be available. In the remaining five countries (20%), availability varied depending on the specific drug (Figure 2).

AIMS

Findings will inform efforts to monitor whether countries are implementing the World Health Organization's first-ever global health sector strategy on viral hepatitis, introduced in 2016.

METHODS

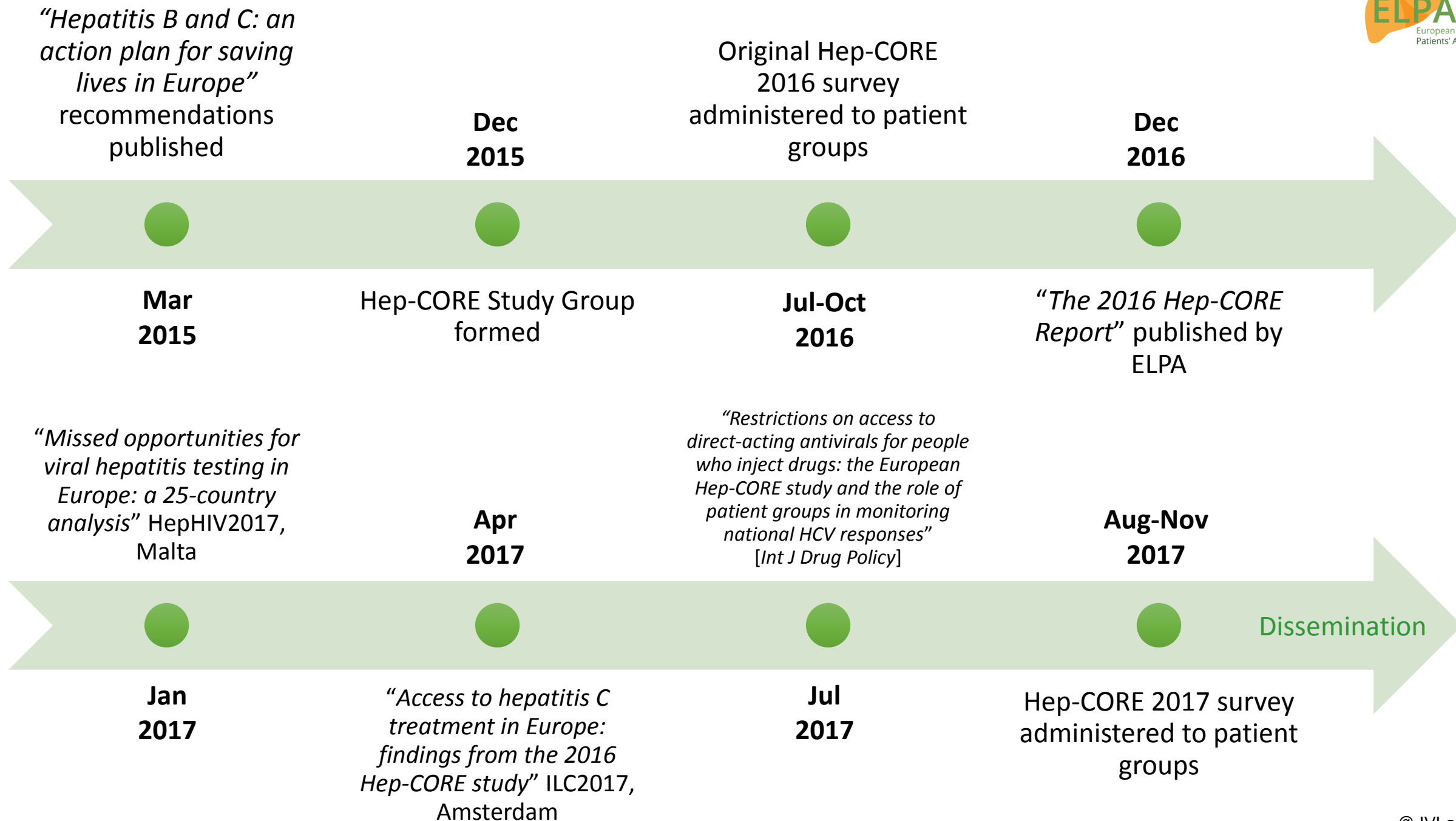
This prospective cross-sectional study utilised a structured 30-item questionnaire administered online to ELPA member organizations in mid-2016. The study was carried out in 25 European countries, with one patient group or coalition of patient groups providing information for each country. The questionnaire addressed hepatitis C treatment in terms that asked about clinical guidelines, availability, cost, treatment settings, and restrictions on treatment access.

Figure 1: Does your country have national clinical guidelines for the diagnosis and treatment of HCV?

Figure 2: Availability of direct-acting antivirals (DAAs) for HCV treatment in non-hospital settings (N=25)

Figure 3: Patient groups reporting available HCV treatment in prisons (N=25)

Figure 4: Restrictions on access to direct-acting antivirals for the treatment of HCV (N=25)



Hep-CORE 2017



- Annual benchmark to monitor changes in the European policy landscape
- Shorter questionnaire covering:
 1. National strategies/action plans
 2. Government collaboration with in-country civil society groups
 3. Cascade-of-care approach to monitoring
 4. National disease registers
 5. Availability of harm reduction services
 6. Testing/screening sites outside of hospitals
 7. Free and anonymous testing services
 8. Assessment for HBV/HCV in routine medical check-ups
 9. Treatment in non-hospital settings
 10. Treatment in prisons
 11. Restrictions on access to DAAs

Hep-CORE 2017

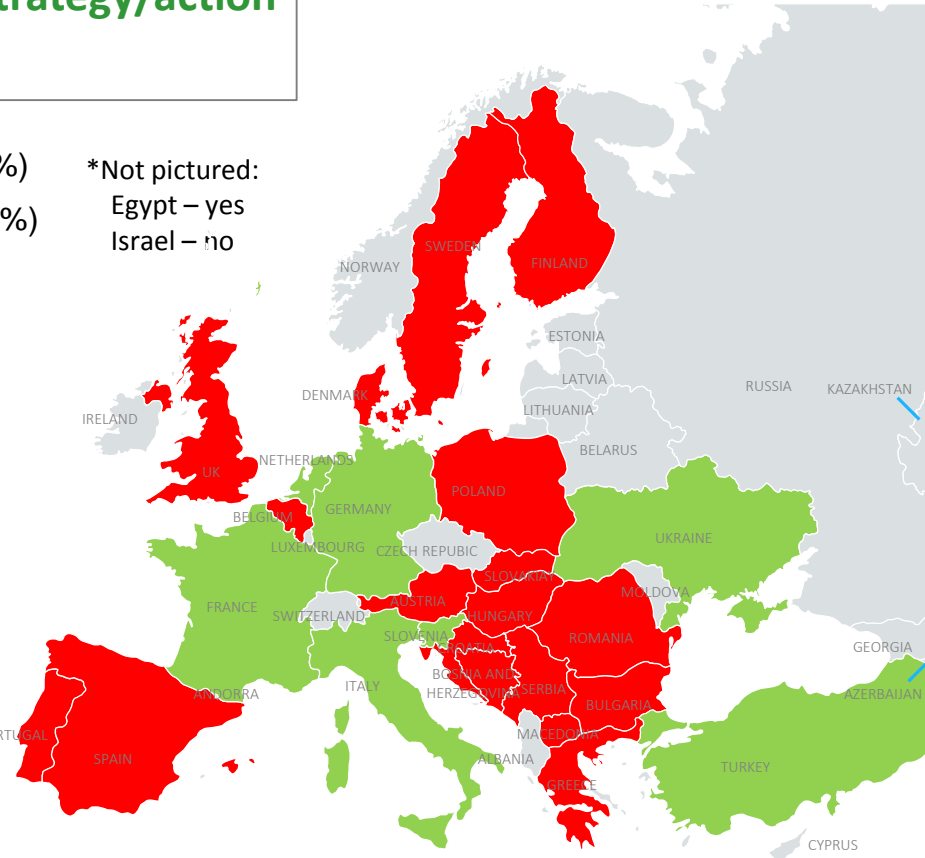


Selected results

Written HBV/HCV strategy and/or action plan

HBV strategy/action plan

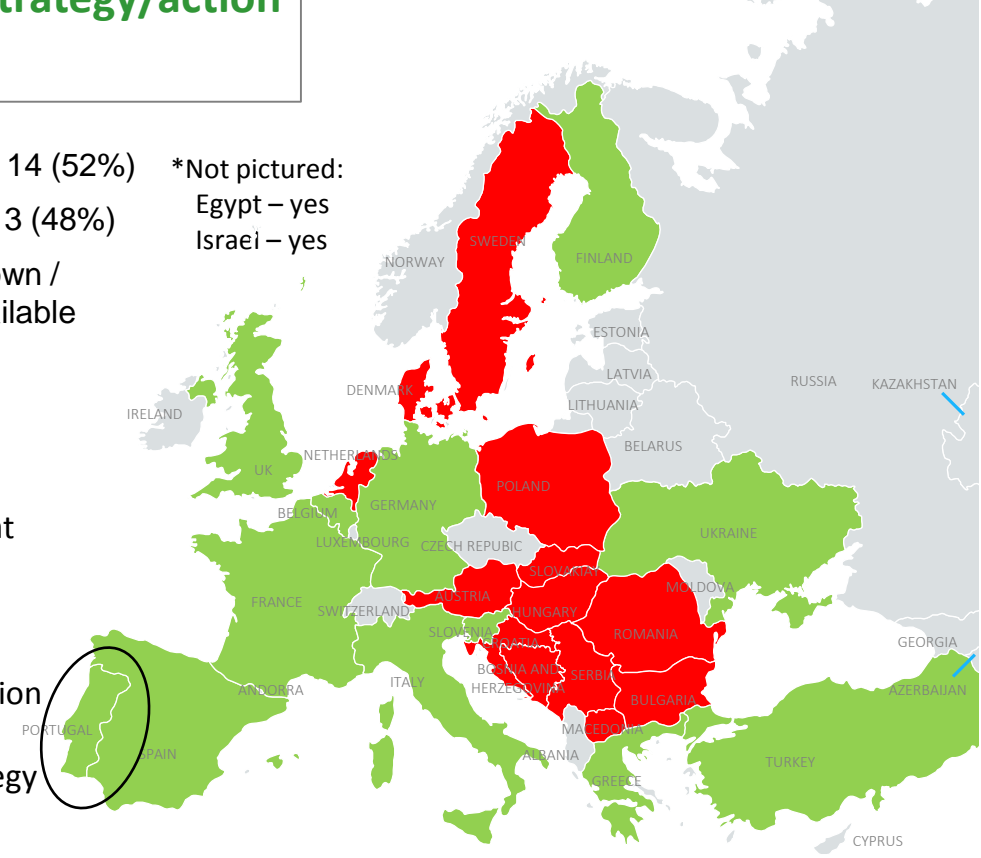
- Yes* = 8 (30%)
 - No* = 19 (70%)
 - Unknown / Unavailable
- *Not pictured:
Egypt – yes
Israel – no



Of the 8 countries that responded positively, 7 have begun implementation of the action plan or strategy

HCV strategy/action plan

- Yes* = 14 (52%)
 - No = 13 (48%)
 - Unknown / Unavailable
- *Not pictured:
Egypt – yes
Israel – yes

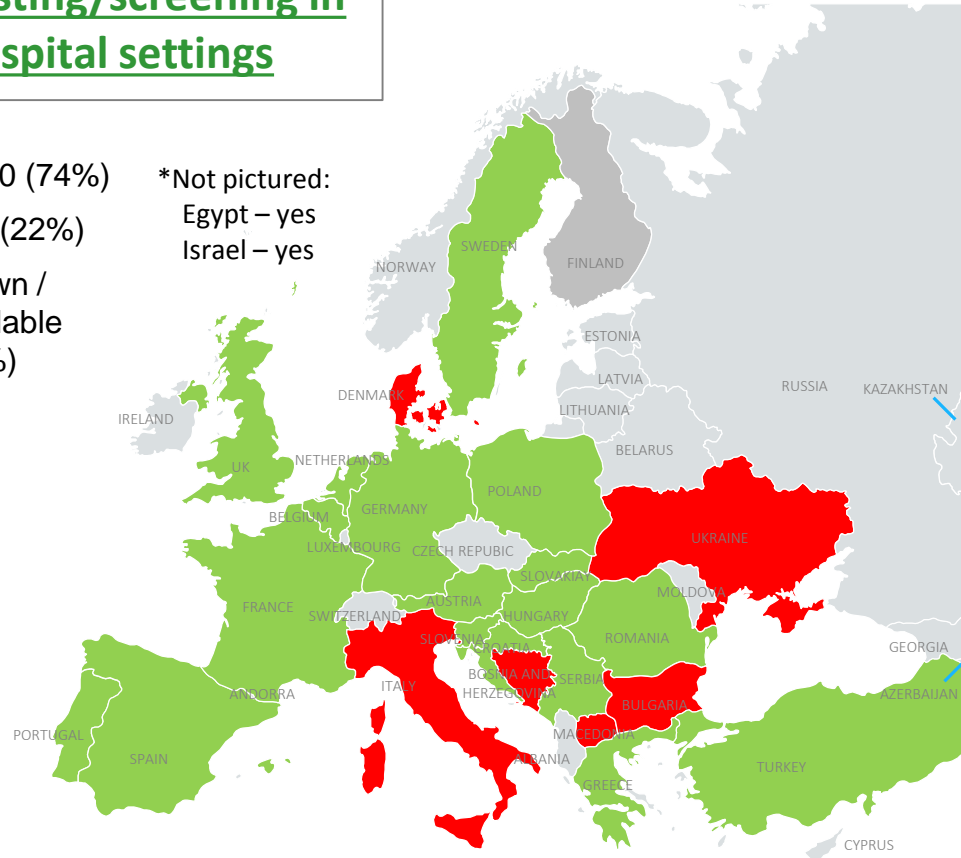


Of the 14 countries that responded positively, 9 have begun implementation of the action plan or strategy

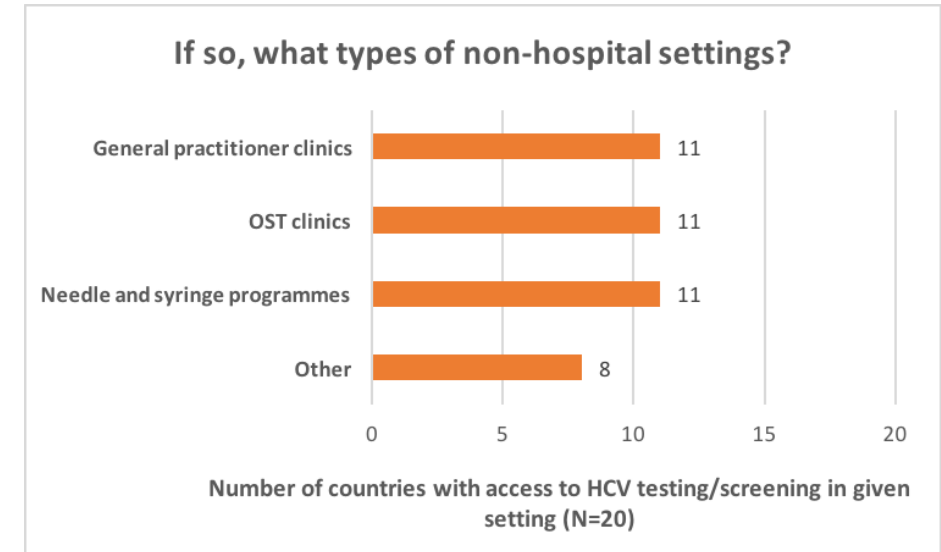
Testing/screening of HBV in non-hospital settings

HBV testing/screening in non-hospital settings

- Yes = 20 (74%)
 - No = 6 (22%)
 - Unknown / Unavailable = 1 (4%)
- *Not pictured:
Egypt – yes
Israel – yes



Of the **20** countries that reported HBV testing/screening in non-hospital settings the distribution was as below:



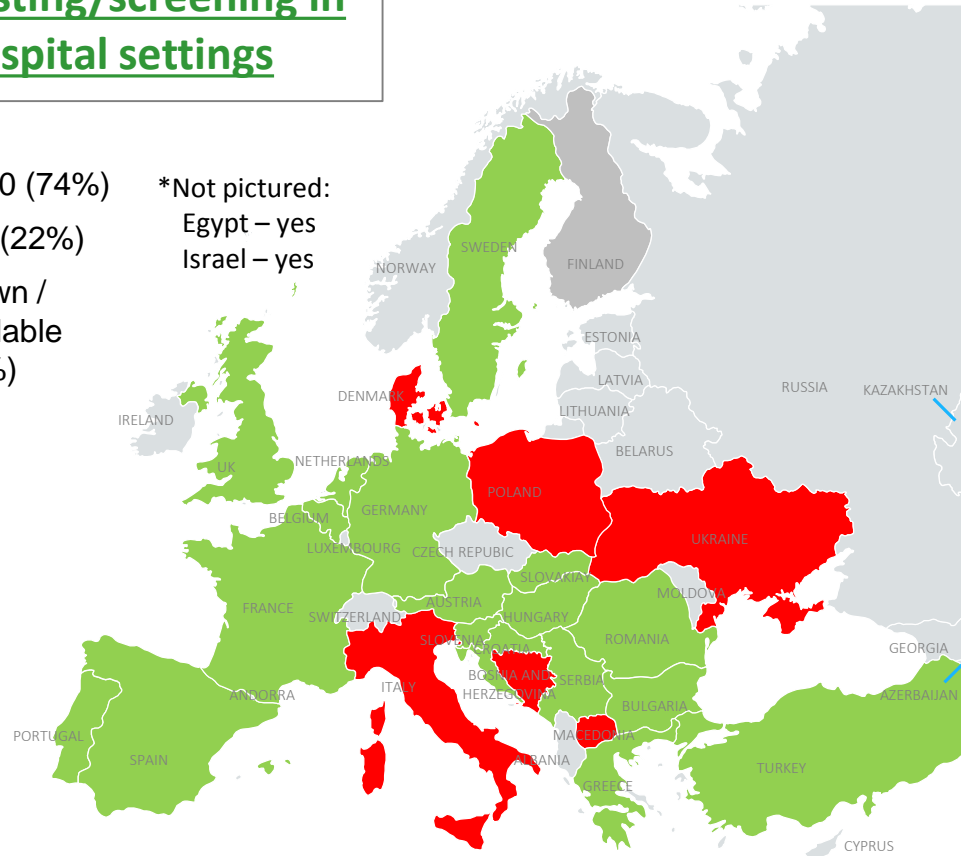
Other:

- NGOs (2)
- Centres for HIV/sexual health (2)
- Mobile clinics (1)
- Outreach programmes (1)
- Local health houses (1)
- Prisons (1)
- Social health care institutes (1)
- Private laboratories (2)
- Private clinics (1)
- Drug addiction centres (1)

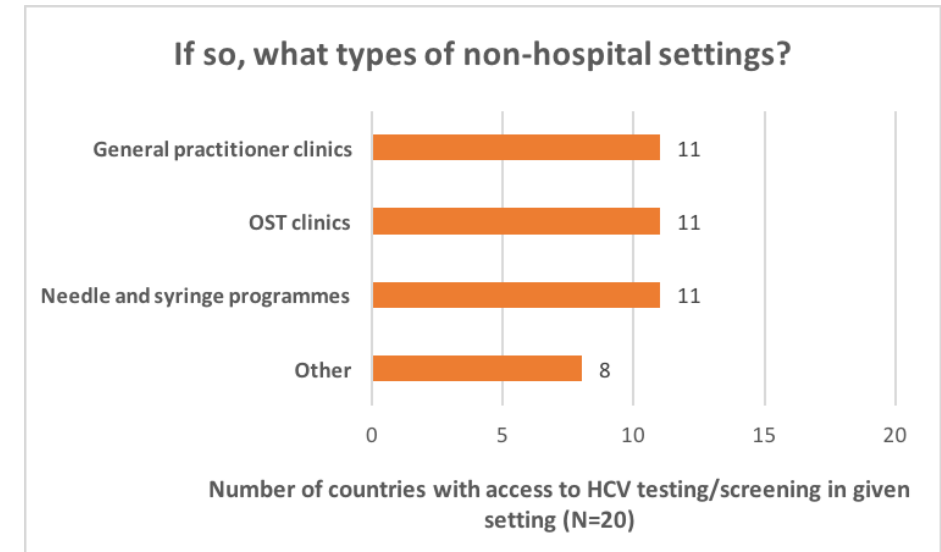
Testing/screening of HCV in non-hospital settings

HCV testing/screening in non-hospital settings

- Yes = 20 (74%)
 - No = 6 (22%)
 - Unknown / Unavailable = 1 (4%)
- *Not pictured:
Egypt – yes
Israel – yes



Of the **20** countries that reported HCV testing/screening in non-hospital settings the distribution was as below:



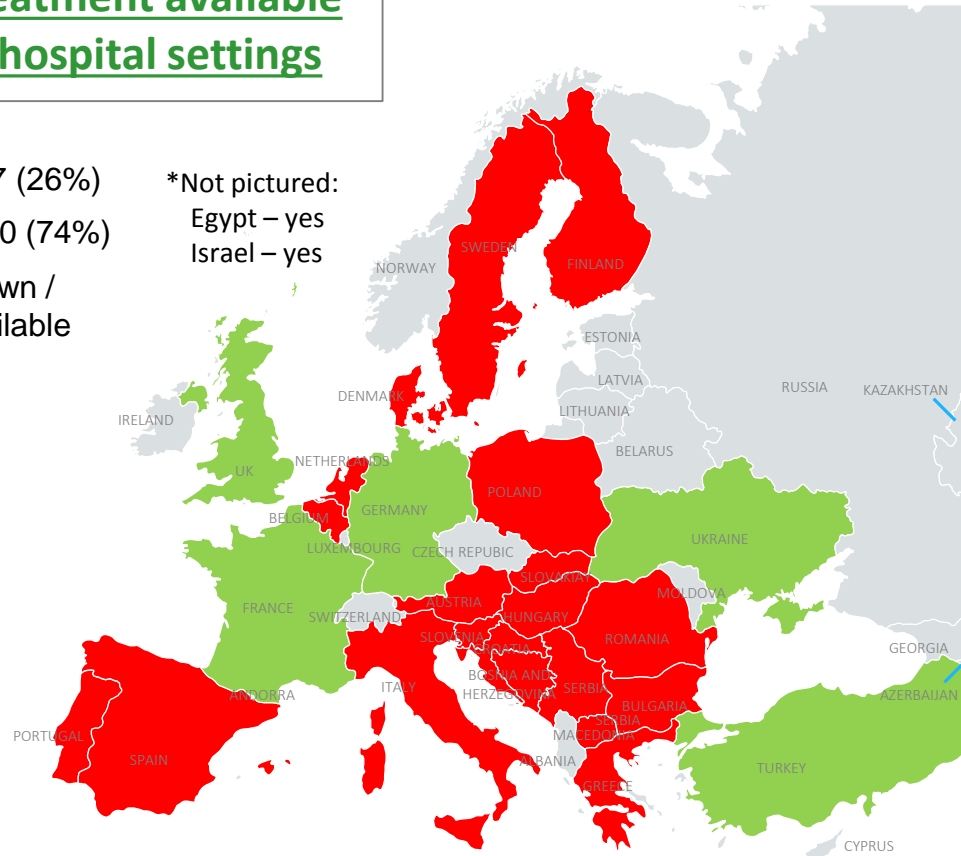
Other:

- NGOs (3)
- Centres for HIV/sexual health (3)
- Mobile clinics (1)
- Outreach programmes (2)
- Local health houses (1)
- Prisons (2)
- Anonymous screening office (2)
- Social health care institutes (1)
- Private laboratories (2)
- Private clinics (1)
- “Substance misuse services” (1)

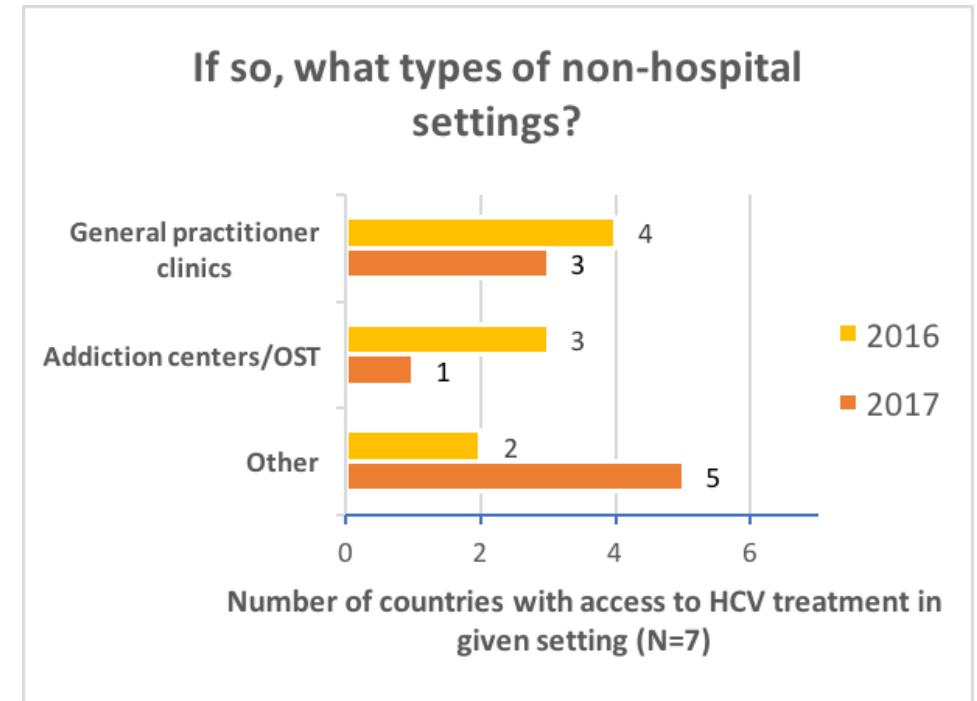
Treatment of HCV patients in non-hospital settings

HCV treatment available in non-hospital settings

- Yes = 7 (26%)
 - No = 20 (74%)
 - Unknown / Unavailable
- *Not pictured:
Egypt – yes
Israel – yes



Of the 7 countries that reported HCV treatment in non-hospital settings the distribution was as below:



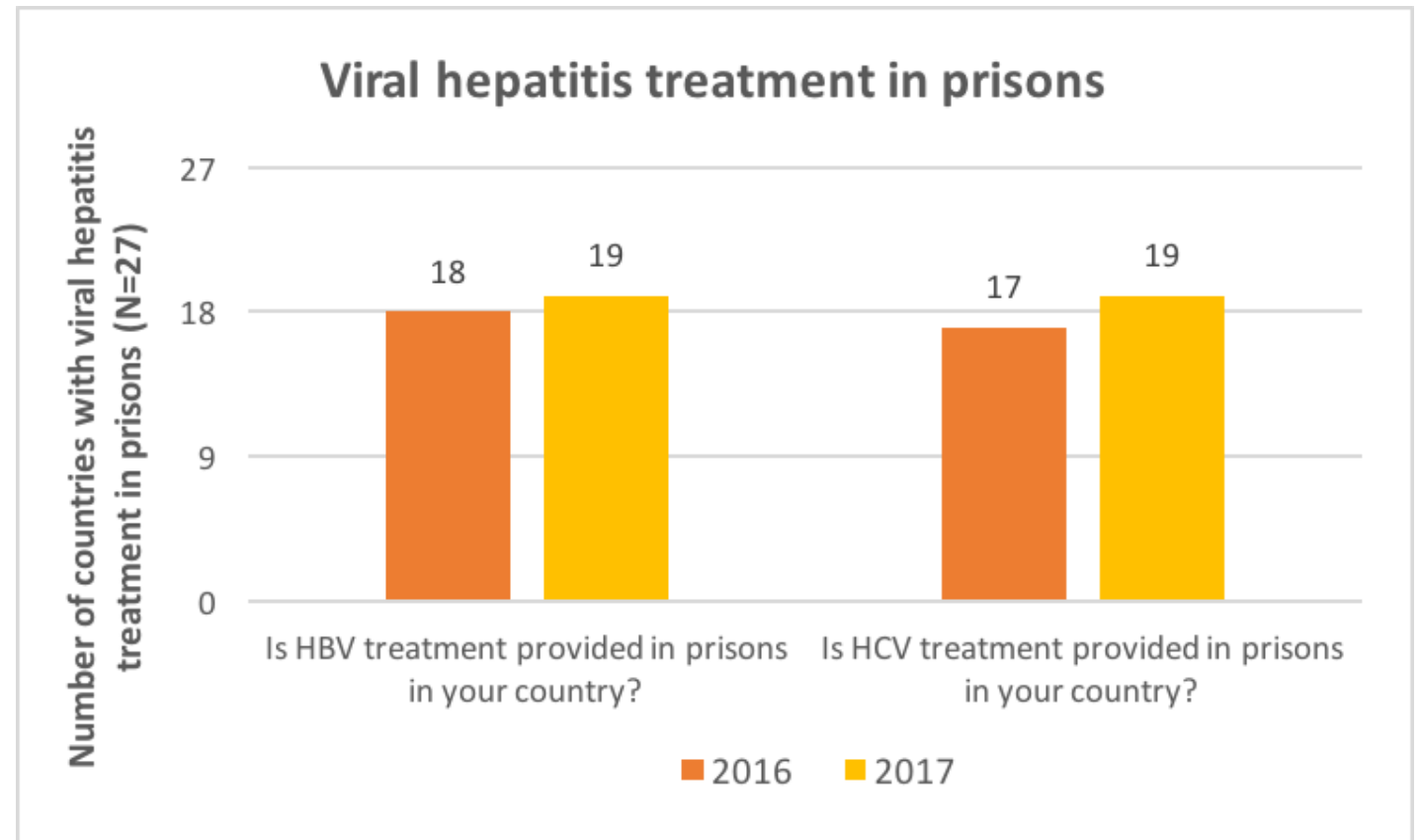
Other:

- Private hepatology clinics / liver specialist (3)
- Gastroenterology clinics (1)
- “Substance misuse services” (1)

Viral hepatitis treatment in prison settings

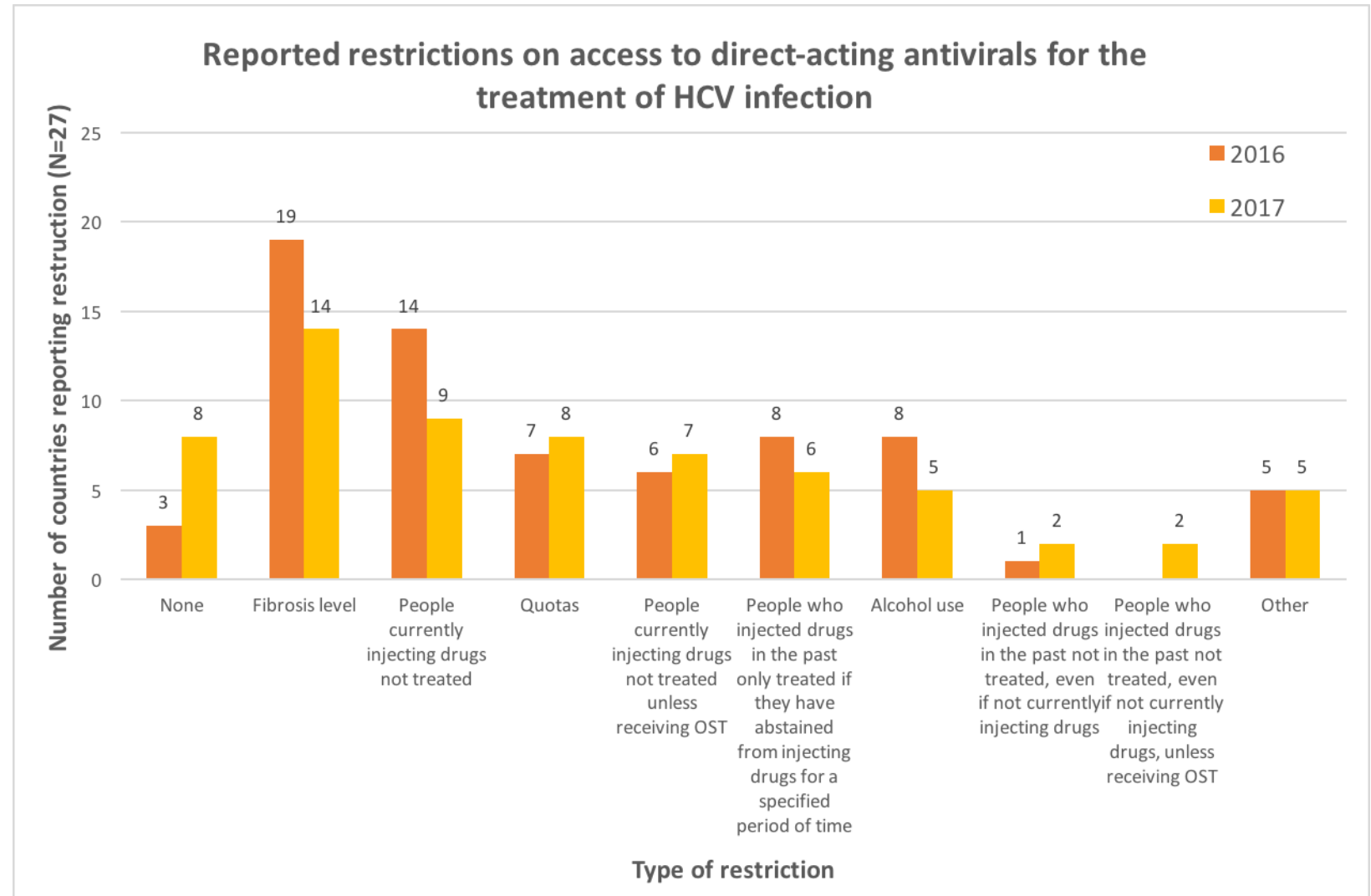
- Variations in responses by country from 2016 to 2017 have an impact on overall results
- Beyond simple change or update in policy

Notable changes in answers from 2016 to 2017	HBV treatment in prisons	HCV treatment in prisons
Positive 2016 response changed to "do not know" 2017	1	1
"Do not know" 2016 response changed to positive 2017	1	2
Negative 2016 response changed to positive 2017	1	2
Positive 2016 response changed to negative 2017	1	1



Treatment restrictions

- Changes in reported data may be due to policy changes or increased patient engagement in the policy landscape
- Majority of restrictions reported have gone down since the 2016 study
- Further engagement is key to keep patient groups informed



Hep-Nordic

- Analysis of the policy response to HCV in the Nordic countries involving:
 - National coordination
 - Prevention
 - Testing and linkage to care
 - Treatment
- Engage stakeholders from multiple realms:
 1. Ministries of Health
 2. Hepatitis patient groups
 3. Drug user groups
 4. National medical societies
- Tool for closing country-specific gaps in viral hepatitis prevention

INHSU – September '17

6th International Symposium on Hepatitis Care in Substance Users

ASSESSING THE POLICY RESPONSE TO HEPATITIS C IN THE NORDIC COUNTRIES: THE HEP-NORDIC STUDY

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chip
Center for Hepatitis, HIV, Immunity and Infections

INHSU 2017

ISGlobal
Barcelona Institute for Global Health

BACKGROUND

In 2016, the World Health Assembly approved the first global health sector strategy on viral hepatitis, an important step towards disease elimination. In the Nordic countries (Denmark, Finland, Iceland, Norway, Sweden), the prevalence of hepatitis C virus (HCV) in the general population is low, but it is 50%-85% among people who inject drugs. A comparison of policies regarding HCV elimination across the Nordic countries is lacking. This study assessed which policies the five countries have established to support key elements of the World Health Organization's global goal of eliminating viral hepatitis as a public health threat.

METHODS

Fourteen national stakeholders representing government agencies, medical societies and civil society organisations completed a 23-item cross-sectional online survey about how their country's policies address the HCV epidemic. Questions were organised into four domains:

1. National coordination
2. Prevention
3. Testing and linkage to care
4. Treatment

A descriptive analysis summarised findings by domain, country and stakeholder group, as well as presented discrepancies.

RESULTS

Stakeholders reported that three (60%) of the five study countries have national strategies for viral hepatitis, though only one (20%) has an HCV elimination goal. Respondents from four (80%) of the countries reported that national guidelines identified certain groups whose members should be routinely offered HCV testing (Figure 1), and a lack of access to anonymous HCV testing was reported in all countries. Four (80%) study countries have national HCV treatment guidelines. All countries provide publicly funded direct-acting antiviral treatment. The availability of harm reduction services within and outside prisons varies; needle and syringe programmes are available in three countries (60%) (Figure 2) and opioid substitution therapy is available in all countries.

Figure 1: Groups identified for routine HCV testing in national guidelines. A horizontal bar chart showing the number of countries (0-4) that include various groups in their national guidelines. The groups are: Men who have sex with men, Healthcare workers, Military personnel, Sex workers, Former prisoners, Current prisoners, People living with HIV, People who inject drugs, People who received blood or blood products before a certain date, and Pre-surgery patients. The legend indicates: Denmark (red), Finland (blue), Iceland (green), Norway (orange), and Sweden (purple).

Figure 2: Needle and syringe programmes available in all parts of the country. A pie chart showing that 40% of countries have 'Yes' and 60% have 'No'.

Figure 3: Stakeholder disagreement by country and survey domain. A bar chart showing the percentage of questions answered in more than one way (0-100%) for four domains: National coordination, Prevention, Testing and linkage to care, and Treatment. The data is broken down by country: Denmark (n=4), Finland (n=3), Iceland (n=2), Norway (n=1), and Sweden (n=4). The legend indicates: National coordination (blue), Prevention (red), Testing and linkage to care (green), and Treatment (orange).

CONCLUSION

The Nordic region as a whole has not thoroughly and consistently expressed its commitment to tackling HCV, despite the existence of large HCV epidemics among people who inject drugs in these countries. Stakeholder alignment and an established elimination goal with an accompanying strategy and implementation plan should be recognised as the basis for coordinated national public health efforts to achieve HCV elimination in the Nordic countries and elsewhere.

CONTACT INFORMATION

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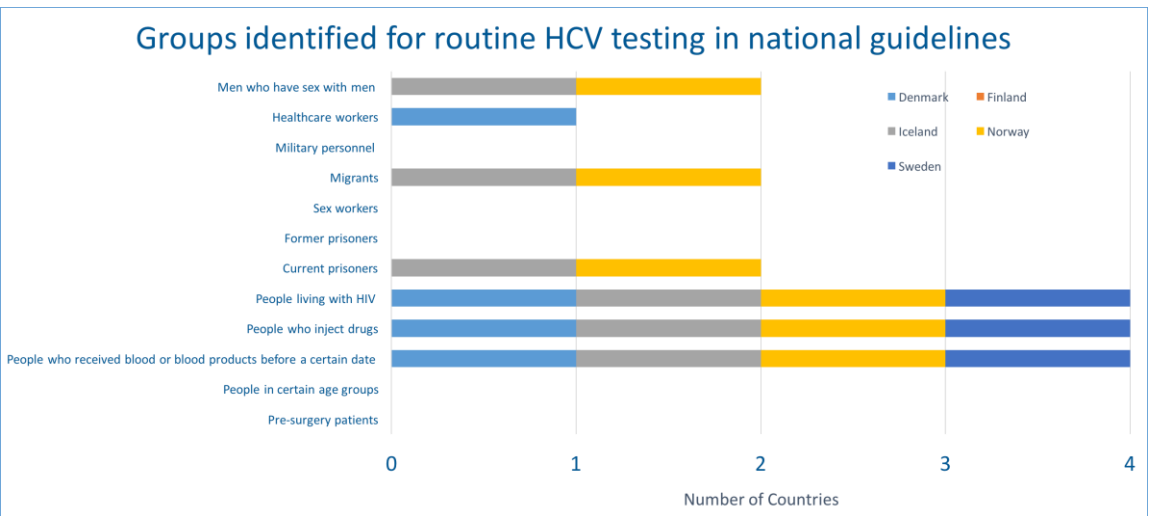
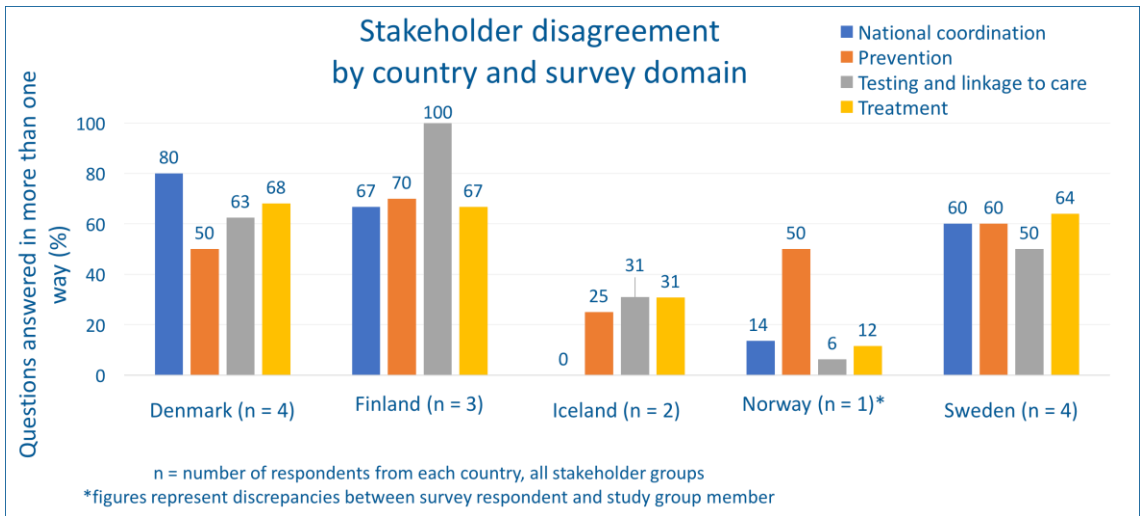
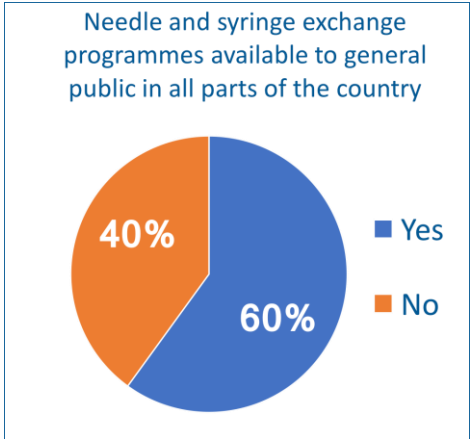
ACKNOWLEDGEMENTS AND DISCLOSURES

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Hep-Nordic

Results

- Widespread disagreement was reported between stakeholders respondents
- Results showed gaps in policies for harm reduction both within and outside prisons
- Strategies for responding to hepatitis C still lacking in the Nordic countries
- Need for scaling up guidelines for prevention, testing, treatment, and goals for elimination



Conclusions

- For future monitoring efforts, ECDC, WHO and beyond, it is essential that patients continue to be engaged in the process and where possible at the centre of the process.
- Patient groups have the potential for increased representation of high-risk populations to have an even greater impact on viral hepatitis advocacy
- Hep-CORE beyond 2017
 - Data extraction from publicly available documents + a focus on practice as more (and improved) policies are in place
 - Continued and increased involvement of key stakeholders in each of the 27 countries (beyond the ELPA member associations)

Our most sincere thanks to ELPA member groups:

- Austria – Hepatitis Aid Austria
- Belgium – Vlaams Hepatitis Contactpunt (VHC)
- Bosnia & Herzegovina – The Chronic Viral Hepatitis Patients Association, "B18"
- Bulgaria – National Association for Fighting Hepatitis - Hepasist
- Croatia – CATIH "Hepatos"
- Denmark – Hepatitis-Foreningen
- Egypt – Association of Liver Patients' Care (ALPC)
- Finland – The Finnish Kidney and Liver Association
- France – Fédération SOS Hépatites
- Germany – Deutsche Leberhilfe e.V.
- Greece – Hellenic Liver Patient Association "Prometheus"
- Hungary – Hungarian Association of Chronic Hepatitis Patients - VIMOR
- Israel – Hetz - Israeli Association For The Health Of the Liver
- Italy – Associazione EPAC Onlus
- Macedonia – Hepar Centar - Bitola
- Netherlands – Dutch Liver Patient Association (NLV)
- Poland – Star of Hope Foundation
- Portugal – SOS Hépatites Portugal
- Romania – APAH-RO
- Serbia – HRONOS
- Slovakia – HEP HELP KLUB
- Slovenia – Slovenija HEP
- Spain – Catalan Association of Hepatitis Patients (ASSCAT)
- Sweden – Riksföreningen Hepatit C (RHC)
- Turkey – HEPYAŞAM - Living with Hepatitis Association
- Ukraine – Stop Hepatitis
- United Kingdom – Hepatitis C Trust and British Liver Trust

...study group members:

- Charles Gore (World Hepatitis Alliance)
- Hande Harmanci (World Health Organization)
- Magdalena Harris (London School of Hygiene and Tropical Medicine, United Kingdom)
- Greet Hendrickx (Viral Hepatitis Prevention Board)
- Marie Jauffret-Roustide (Paris Descartes University, France)
- Achim Kautz (European Liver Patients Association)
- Mojca Matičič (University Medical Centre Ljubljana, Slovenia)
- Luís Mendão (Grupo de Ativistas em Tratamentos (GAT), Portugal)
- Antons Mozalevskis (WHO Regional Office for Europe)
- Raquel Peck (World Hepatitis Alliance)
- Tatjana Reic (European Liver Patients Association)
- Eberhard Schatz (Correlation Network)
- Kaarlo Simojoki (A-Clinic Foundation, Finland)
- Joan Tallada (European AIDS Treatment Group)

...and funders: AbbVie, Gilead Sciences, MSD

Thank you

Questions? Comments?

For more information or questions about the study:

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Hep-CORE

The logo for Hep-CORE features the text "Hep-CORE" in a bold, black, sans-serif font. The letter "O" in "CORE" is replaced by a green circular icon containing a white silhouette of a globe, representing the global nature of the study.